

## CHAPTER III

### WHOM DO WE CALL MENTALLY RETARDED?

by Gunnar Dybwad

This book is about people, people referred to as being mentally retarded. Through the centuries much has been said about them, about their being dangerous, evil, possessed, or, to the contrary, special gifts from Heaven, "holy innocents."

Many of these beliefs live on. One can encounter them even today almost anywhere in the United States as plans are discussed for community residences for mentally retarded persons.

Yet mentally retarded individuals have lived in our communities since time immemorial. Over the past decades many of them have gone to public schools, not by the thousands, but by the millions; in increasing numbers they are employed in business, industry and government. They travel by bus and subway, go to ball games and movies, and some even vote at the polls.

This is not an idealized picture, but it is just not a complete picture. Many mentally retarded individuals, severely and multiply-handicapped, whose functions and activities are extremely curtailed, spend their days in idleness in institutions.

First, then, we must learn that being called mentally retarded has very little meaning. Mental retardation is not a very descriptive or revealing term; it cannot convey an adequate picture. There is too wide a difference between the retarded young adult who leaves his community residence in the morning, joining the subway crowd on his way to work, and another retarded person who spends his day in the ward of one of our large state institutions, idly shuffling about.

In the face of such a wide range within the group considered *to* be mentally retarded, efforts have been made through the years to establish a terminology for the different degrees of this handicap. In the early part of this century people differentiated between idiots, imbeciles, and morons, depending on the extent of their mental retardation, with the moron being the least severely involved.

With the introduction of the intelligence test, developed by Binet in France, and brought to this country by Goddard, it became an accepted practice to relate these three terms to specific I.Q. scores \*—idiot for those scoring below 25, imbecile 25 to 50, and moron 50-70/75. Later on the terms "severe," "moderate," and "mild" replaced those terms, but conceptually no change occurred. It was firmly believed that not only could the degree of mental retardation be definitively tied to fairly restricted scores on intelligence tests but, more importantly yet, that this was an unchanging static designation. Not only "once retarded, always retarded," but also "once moderately retarded, always moderately retarded." The I.Q., it was commonly accepted, was fixed. Moreover, it was believed that the I.Q. ratings and the three part classification—mild, moderate, severe—could be tied very closely to a level of functioning, circumscribing quite narrowly what such a person could not do in terms of daily living and learning. Whether a Person received an I.Q. of 71 or 68, of 52 or 49, could have the most far-reaching consequences for his lifetime, because that difference was the key to decisions about the service which he would receive or from which he "had to be" excluded, and more likely it was the latter. As one educator\* has succinctly expressed it, "While the difference between *becoming* or not becoming mentally subnormal may often be slight, the difference between *being* and not being mentally subnormal may be considerable."

Overall, the steady progress of urbanization, industrialization, and specialization and the sharply increasing life tempo and competitiveness decreased the tolerance for retarded individuals, and less and less was there a place for them in the community, socially or even physically.

In the late nineteen forties and early fifties into this situation broke the movement or, more appropriately, the rebellion of parents of mentally retarded children. Throughout the United States and Canada, in England, France and Scandinavian countries, in Australia and New Zealand these parents stood up and demanded that their children not be denied the privilege of schooling, vocational training, and meaningful occupations.

Although some educators quickly supported the parents' demands (and, indeed, a few school systems had heretofore for many years successfully conducted classes, not just for mildly but also for moderately retarded children), overall the field of education reacted negatively. The education profession remem-

\* The concept of the Intelligence Quotient as related to Binet's mental age was developed by W. Stern.

\* Albert T. Murphy as quoted in Burton Blatt's *Christmas in Purgatory*. Boston, Mass.: Allyn and Bacon, 1966.

bered that high hopes for the educability of mentally retarded individuals during the second half of the nineteenth century had led to severe disillusionment, and to this was added the negative impetus of the "eugenic scare" during the first two decades of the twentieth century, which looked upon the mentally retarded person as a menace to the well-being of society.

When parents pushed on and in many communities actually organized classes for the moderately retarded (that is, children with an I.Q. between 50 and 25), educators responded with a terminological sleight-of-hand, the effect of which is still haunting community planning. They introduced a supposed philosophical and methodological difference between educability and trainability. Mildly retarded children, those with an I.Q. above 50, were termed educable; the moderately retarded were considered ineducable but trainable. Also, many prominent leaders in special education believed that this "training" was not a responsibility of the public schools but a "welfare" job. Those below the "trainable" level, the educators chose to call "custodial" cases, suggesting that nothing more than safekeeping could meet their needs.

In the ensuing years this viewpoint failed to prevail as, under pressure from parents, legislation was enacted in more and more states making the education of the so-called trainable child a mandated task of the public schools. However, the terminology remained, and with it the static viewpoint toward mental retardation on which it was founded.

This terminological effort of the special educators created serious and pervasive damage in two ways. Without sufficient evidence a sharp dichotomy was created between the learning process and learning capacity along the hairline of an I.Q. of 50. Furthermore, what might have been justifiable as a designation of two different teaching methods was perverted into a label affixed to individual children with the clear implication that a child, once designated trainable, could hardly be expected to move up to the more advanced type of instruction appropriate for educability. Unfortunately, the labeling did not stop here, but post-school community services such as vocational training centers and workshops adopted it as well, thereby carrying over the label of ineducability into adulthood, through the tasks to be performed by mentally retarded adults in a work situation might differ sharply from those in a classroom situation. Fortunately, the rather negative exclusion-oriented attitude of professional educators changed radically, most noticeably following the mid-sixties. This shift in attitude culminated in a strong policy statement passed at the 1971 annual conference of the

Council of Exceptional Children, the national organization of teachers, supervisors, and administrators in special education. This significant six-page document entitled "Basic Commitments and Responsibilities to Exceptional Children" explicitly states that education is the right of all children and that educational opportunities should not be denied to any child regardless of his potential for contributing to society.

While the foregoing developments took place in the field of special education, other changes occurred in the general terminology and classification of mental retardation. The American Association on Mental Deficiency, in 1959, issued a revision of its *Manual on Terminology and Classification* which contained three important changes. In contrast to other classification schemes, such as that in use by psychiatrists which tended to lump together all retarded persons with an I.Q. below 50 as essentially incapable of development and in need only of protective care, the 1959 AAMD classification, on the basis of demonstrated differential capacity and performance, suggested a three-level division of those with I.Q. below 50 into moderately, severely, and profoundly retarded. Furthermore, in the definition of mental retardation, this revision added to the factor, "subaverage intellectual functioning," a second factor relating to social adaptation, "impairment in adaptive behavior." Finally, the Manual brought into the realm of mental retardation a grouping formerly known as having borderline intelligence. It did so by decreeing that (subject to the criterion of impairment in adaptive behavior) a differing mathematical cut-off point was to delineate mental retardation (to wit: one standard deviation below the norm) and that this psychometric grouping of people would henceforth be designated as borderline mentally retarded.

The first change, the creation of the new category of profound mental retardation, proved to be very useful from a practical viewpoint; it focused attention on this long neglected group of individuals who populated the back wards of the state institutions. Studies and demonstration projects soon revealed that this group could respond far better to simple training efforts than had been assumed, and was even more responsive to environmental change when the back wards were changed into something a little bit more resembling human habitation. Furthermore, in many cases the severe physical impairments with which these individuals were afflicted appeared to be a major factor in their extremely low level of performance, and upon remediation (for example, through orthopedic surgery, physical therapy, and so forth) a distinct improvement in their level of functioning occurred. This suggested that the group might be better referred

to as profoundly handicapped rather than as profoundly mentally retarded.

There was a great deal of positive response from the field to the second recommended change, the addition of the concept of adaptive behavior. Unfortunately, however, tests for the application of this new criterion were still in the early stages of development and fifteen years later are still not part of most psychological evaluations. In other words, in spite of increasing doubt about the sufficiency of the intelligence test in the determination of mental retardation, it has remained from a practical viewpoint the sole determinant.

Yet more significant, from this chapter's focus, was the response to the third recommendation, the establishment of the new "borderline" category within mental retardation, which vastly increased the supposed number of retarded individuals in the United States. What happened was that fourteen years later, in 1973, the American Association on Mental Deficiency published yet another revision of its Manual and with one turn of the printing press removed from millions of American citizens the burden imposed on them in 1959 of being presumed to be mentally retarded, albeit on the borderline level only. AAMD simply lowered the upper cut-off point for mental retardation not one but two standard deviations (e.g. an I.Q. of 68 on the Stanford Binet test), subject of course to the second criterion, impairment of adaptive behavior.

Here, then, this chapter's question "Whom do we call mentally retarded?" comes into sharp focus and brings forth a rather disturbing answer. We call mentally retarded those whom "we" choose to call so. And, who is the "we"? In this case of classification and terminology it was a professional organization working in the field of mental retardation which entrusted this task to a committee and did not even see a need to have the sweeping revisions ratified by a vote of the membership. Thus in an unmistakable way the American Association on Mental Deficiency has clearly supported the thesis put forth by one outstanding social scientist active in the field of mental retardation, Dr. Jane Mercer of the University of California. Dr. Mercer maintains that mental retardation is not so much a clinical designation based on compelling evidence as it is a social status conferred on individuals by whatever societal group has been given, or has taken upon itself, the right to so label people.

The President's Committee on Mental Retardation has illustrated this view with its widely distributed booklet *The Six-Hour Retarded Child*, the child who five days a week, from

nine to three, *has the status* in school of being retarded but who is not so considered while moving about in the community.

But this is not the only example. Those concerned with statistical studies in mental retardation have long been aware of an intriguing phenomenon—the number of "known" mentally retarded persons in any community drops sharply for the older out-of-school group. Once a young adult has left school and on his own has secured employment in the community, he may "lose" his status as a retarded individual and may be accepted at his place of employment, as well as in the community at large, as just another young citizen.

In other words, as we set out to develop new plans for community services for mentally retarded persons, we need to remember that tens of thousands of substantially mentally retarded children, adolescents, and adults are now and have been for many years living, walking, and working in our cities and towns, have attended public schools, have gone to camp, have used streetcars and subways, have voted and held a vast variety of jobs. While many of them, maybe the majority, were and are known to some as retarded individuals, many are not so recognized in day-to-day living. Yet other individuals are so handicapped or conduct themselves in such a fashion as to be seen as manifestly retarded. We must understand that the *status of being retarded is open to change*, and the record will show that our predictive capability is limited.

Less dramatic perhaps, but to the individual involved of great significance, is a further and related phenomenon: The level or degree of mental retardation originally bestowed upon an individual by a clinic, school, or institution may also change. The individual who once sat in an institutional back ward, half naked, aimlessly rocking back and forth, and "obviously" profoundly retarded may later be seen in a sheltered workshop in the community, operating some simple mechanical equipment, properly dressed and maintaining human contacts—verbal or non-verbal—with others around him.

Of course, at least presently, certain groups of children or adults need more or less extensive nursing care for an unspecifiable time. But their condition clearly does not require confinement in a large state institution. They have a right and the capacity to be in an appropriate community facility, with an open door leading to a less restrictive, less restraining environment. Only time will tell who will use that open door.

And that brings us to the question: How many retarded persons are there in our community? This invokes a counter question: How retarded is retarded? Shall we be guided by the

1959 or the 1973 definition of the American Association on Mental Deficiency? The by now traditional statistical view was predicated on a three percent figure. But no one has yet been able to find the three percent mentally retarded persons in any large unselected population group. Two scholars who have given this question much study, Professors Burton Blatt and George Tarjan, put the incidence of mental retardation in the general population at no more than one percent, and quite likely less.

Furthermore, even if one could say with certainty that a given community has today one hundred individuals waiting for a place in a community group home or other facility, it would be hard, indeed impossible, to predict for how long each one of them would need to stay there or how soon they could move to "regular" unsupervised living quarters. Broad statistical generalizations will be of very limited use in this context.

Our knowledge of the developmental potential of individuals labeled retarded is as yet insufficient for long range estimates. A parallel will make this clear: Had we rushed in, nationwide, in the nineteen fifties and sixties to build special schoolhouses for children considered to be only "trainable," we would now have white elephants on our hands from coast to coast.

The question "Whom do we call retarded?" is best responded to by a counter-question: Why *call* anyone retarded? Webster's dictionary says "to call" means among other things "to utter in a loud or distinct voice," "to read over (a list of names) loudly," "to give a name to" and "to regard or characterize as to a certain kind."

Perhaps the significance of the question and counter-question will become more apparent if we take our cue from the last definition and explore what "certain kind" we mean when we use the term mental retardation.

At least to some extent the answer to this question will surely come from young and not so young mentally retarded adults themselves, whose emergency from the once nebulous mass characterized as mentally retarded is providing us with an exciting and challenging drama. One can already clearly discern the first indications that some of these people, once known as "docile retardates," are no longer willing to sit in the back of the bus. Education is a powerful tool; the withholding of education and of knowledge has been practiced through the ages by benevolent as well as oppressive rulers in Church and State. Education and a new tool, "advocacy," are now helping the retarded citizen to assert himself and to protest a label that he sees as a libel.